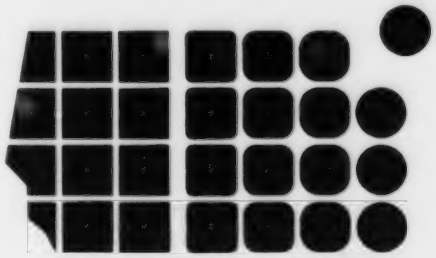

THE PREMIER'S COUNCIL
ON THE STATUS OF PERSONS WITH DISABILITIES

TOWARDS A NEW VISION OF ABILITIES IN ALBERTA

DRAFT

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PREFACE

An extensive consultative and planning process was symbolically initiated at a March 1987 meeting between Rick Hansen ("Man in Motion") and Premier Don Getty. It was after this meeting that the Premier set in motion the establishment of the Premier's Council on the Status of Persons With Disabilities to demonstrate the Alberta Government's commitment to the full and equal participation of all Albertans with disabilities in Alberta society.

A Steering Committee was struck in September of 1987 to manage the development of a proposal leading to the establishment of the Premier's Council. An intensive information gathering process was undertaken by the Steering Committee to ensure that individual consumers, their families, consumer groups, related professionals, as well as agency and government representatives from across the province had input into the Committee's recommendations. Following the submission of the Steering Committee Proposal and its acceptance by the Government, Gary McPherson was appointed as Chairman of the Council. Nominations for Council were requested and with the appointment of twelve Council Members in October 1988, the start-up challenges of the Premier's Council had been met.

The remaining challenges are much more complex. The Albertans which the Premier's Council serves are living in a province confronting rapid change. Alberta's economic restructuring continues following the ending of the "oil boom" of the 1970's and early 1980's. With over sixty percent of its population now living in urban centres, Alberta is also adjusting to the reality of becoming an urban society. The changing demographics of the Province have broad implications for issues ranging from the availability of labour to the nature of health care. As well, many Alberta families no longer fit the historical two-parent model. Thus, the province is undergoing fundamental social change and such fundamental changes are necessitating extensive public policy review.

In addition to a dynamic context, the Premier's Council faces the challenge of addressing the rights and needs of an extremely diverse group of consumers. The Premier's Council is mandated to serve the interests of all Albertans with disabilities but the varying nature and breadth of these needs are not always understood by the public, the professionals, and the private and public agencies that serve persons with disabilities.

The possibility now exists to establish Alberta as a Province leading the way in policy towards persons with disabilities. The Council's opportunity lies in catalyzing comprehensive, integrative policy review to achieve this social change, however, the Premier's Council must proceed with this task in a consultative manner, ensuring its views reflect the

interests of all Albertans with disabilities. It must also pursue a clearly focused vision, avoiding duplications with existing initiatives and channelling its limited resources as effectively as possible.

The intent of this paper is to target the role for the Premier's Council on the Status of Persons with Disabilities; that is, to outline the contextual challenges arising from our past and present, to paint a picture of our potential future, and to define the Council's role in leading this transformational change.

TABLE OF CONTENTS

OVERVIEW 1

A NEW ERA APPROACHES FOR ALBERTANS WITH DISABILITIES 3

Public Policy has Reflected Paternalistic Assumptions 3

Public Policy has Historically Perpetuated Negative Values and Attitudes 3

Public Policy and Public Attitudes are now Reflecting Positive Changes 4

Complex Challenges Still Remain 4

We Stand on the Threshold of a New Era 6

POLICY IN THE NEW ERA 7

Public Policy Needs Transformation 7

Public Values and Attitudes need Transformation 7

Disability Policy must include a Focus on Prevention 8

THE PREMIER'S COUNCIL FACES A CHALLENGE OF LEADERSHIP 9

The Premier's Council must Focus its Limited Resources 9

The Premier's Council must Lead in Policy Development 9

The Premier's Council must Lead in Public Education 10

The Premier's Council must represent its constituents 10

THE COUNCIL'S MISSION 11

THE COUNCIL'S PRINCIPLES 13

CONCLUSION 15

OVERVIEW

"Towards a New Vision of Abilities in Alberta" is a challenge to persons with disabilities, their representative organizations, and government to forge a partnership and endorse a shared vision that will enable a transformation of public attitudes and public policies to occur in Alberta. This transformational change will result in the achievement of "status as equals" for all persons with disabilities in this province.

The paper addresses three key areas:

1. Transformation of Public Attitudes and Public Policy

In order to elevate the status of persons with disabilities to one of equality, a shift in focus must occur:

- from the limitation to the person
- from the disability to the ability
- from charity and pity to individual right and responsibility
- from a concept of costs to one of investment
- from institutional living to community living

2. A New Policy Framework

Future policy related to persons with disabilities must encompass three facets:

- Social perspective - a commitment to a dignified and humane society ensuring quality of life for all Albertans
- Economic perspective - a recognition of the significant economic contribution to be made by persons with disabilities, that support and assistance are an investment in the individual
- Citizenship perspective - a commitment to equality for all Albertans

3. Principles to Guide Policy Development

The Council believes that, if it is to accept the challenge of improving the status of persons with disabilities, we must propose a belief system which we can all accept and which will guide us in the foreseeable future.

CROSS DISABILITY PERSPECTIVE

The mandate of the Premier's Council is to work toward full participation of <u>all</u> persons with disabilities in the life of Alberta. Within this paper, reference to persons with disabilities is intended to include all those with physical and mental impairments, mental illness, hearing and visual impairments, and brain injury.

A NEW ERA APPROACHES FOR ALBERTANS WITH DISABILITIES

Public Policy has Reflected Paternalistic Assumptions

Historically across North America, the definition of disability has been heavily influenced by medical etiology. Disabilities have been viewed through the perspective of discrete diagnostic categories; the symptoms and consequence of the diagnosis were naturally the associated mental and physical limitations. This focus on illness traditionally has served to cultivate the belief that persons with disabilities are not "normal", not "able", and not "well". Solving the problem of disability meant "fixing" the person with disability. Those individuals who could not be "fixed" were assumed to be incapable. This assumption essentially applied, regardless of the nature of the disability.

Public (government) policy has traditionally reflected the limiting assumptions of this medical definition of disability. As a result, public policy has been paternalistic in its approach to persons with disability. Emphasis was placed on "curing" the person with disability but, in the absence of a cure, the alternative was protecting and caring for persons with disabilities. As a consequence, they were removed from their families and home communities and placed in institutions. Across North America, such segregation became the policy norm.

Public Policy has Historically Perpetuated Negative Values and Attitudes

This policy approach by government has served to reinforce negative values and attitudes towards persons with disabilities. Albertans with disabilities from across the Province have been congregated in institutions such as Alberta Hospital Ponoka, Alberta Hospital Edmonton, Michener Centre, Alberta School for the Deaf, and Aberhart Centre.

Consequently, most "normal" Albertans have lived their lives experiencing minimal contact with persons with disabilities. This public policy stance has served to reinforce the belief that all persons with disabilities belong in institutions. Moreover, such segregation has served to perpetuate the fear that not only must persons with disabilities be protected from society, society must also be protected from persons with disabilities.

The responses of private citizens to disability have mirrored such assumptions based on limitations and incapability. Fund raisers have mounted financially successful campaigns which portray persons with disabilities as objects of pity and charity and these images have reinforced beliefs in the helpless "plight" of persons with disabilities.

Our language has also reflected our mental images of charity and pity. Words and phrases such as "suffering from a handicap", "afflicted", "crippled", and "deformed" illustrate the illness assumptions in our descriptions of persons with disabilities. Language and humour also have represented negative attitudes toward persons with disabilities. Labels such as "spastic", "retard", "freak", and the "village idiot" have been used to depersonalize and devalue persons with disabilities. More recently, persons with disabilities pursuing independence and achievement have been described as "courageous", "heroic", and an "inspiration". Although these terms are more positive in tone, they again do not promote assumptions that persons with disabilities undertake "normal" activities. Segregation from society, congregation in institutions and language associated with disability have all served to perpetuate ignorance and fear in members of society as to the actual needs, desires, and capabilities of persons with disabilities.

Public Policy and Public Attitudes are now Reflecting Positive Changes

Public policy and public attitudes have become more enlightened in the last two decades. The American civil rights movements of the 1960's served to raise the consciousness of all North Americans about the human rights of all citizens. New philosophies of treatment have demonstrated that community integration can be an effective alternative to institutionalization. Public officials, professionals, and service agencies are increasingly recognizing the importance of community support systems to promote healthy families and healthy communities.

The Charter of Rights has lead to increasing recognition of citizenship for all Canadians. This has been demonstrated by the recent Federal Court decision giving the right to vote to persons residing in institutional settings. As well, employment equity programs represent the growing public and private awareness of the right, the ability, and the desire of persons with disabilities to make a contribution to society. And, public figures such as Rick Hansen and his "Man-In-Motion Tour" have also educated the public to see the ability as opposed to the limitations in all persons with disabilities.

Complex Challenges Still Remain

As we approach the 1990's, however, many challenges remain. Progress has undoubtedly been made in questioning our limiting assumptions about persons with disabilities, and public attitudes have become more enlightened. However, such progress has been somewhat uneven. Misunderstanding, fear, and negative judgments still exist regarding persons with disabilities.

Progress in the past has often been slowed by ideological conflicts. This has served to divide advocacy and consumer groups, with such groups often postulating opposing

visions of lifestyle and service delivery. Such conflicts have contributed to pendulum-like swings in approaches to service delivery. These swings were often implemented in the absence of appropriate planning, funding and infrastructure. This is perhaps best illustrated by the reality faced by individuals who have been discharged from institutions and placed in urban independent living situations without appropriate community support services.

Public policy has been fragmented in its approach to persons with disabilities. Government agencies have often deveioped policy for specific segments of the population of persons with disabilities. For example, the Workers' Compensation Board addresses policy for the worker with a work related disability, while vocational rehabilitation addresses the needs of those whose disability has other origins. This lack of integration has resulted in the promotion of a variety of approaches. Given such a fragmented approach to policy, policy gaps or duplications exist for those persons who do not clearly fall into definite jurisdictional boundaries, e.g. people with brain injuries.

Community integration has also proven to be a complex issue because this lifestyle approach may not be appropriate or be preferred by all persons with disabilities. Individual choice and corresponding options are increasingly being desired by consumers.

The product of a fragmented approach to public policy development has been a confusing, fragmented service system. Many programs work at cross purposes to each other. For example, Alberta Career Development and Employment's programs promote the integration of persons with disabilities into the workforce, yet this is hampered by the funding policies and guidelines surrounding the Alberta Assured Income for the Severely Handicapped program. No financial alternative exists to cover the cost of services provided under AISH and persons with disabilities obtaining entry level positions cannot afford to pay for the services they require. Consequently, persons who wish to work are reluctant to enter the workforce because the subsequent loss of AISH benefits results in a financial hardship.

For those Albertans with disabilities who have the potential, the opportunity to make an economic contribution is central to realization of positive social roles, yet persons with disabilities represent a largely untapped labour pool. For any number of reasons, employment opportunities for persons with disabilities are limited, e.g., the cost of technical aids, inaccessible work sites, job design, and/or the limited understanding of employers.

Finally, issues surrounding disability can only become more complex. For example, medical technology has led to the survival of many persons who may be left with severe impairments that are not well understood or accommodated by the existing service system. It is projected that the costs related to these often preventable disabilities will escalate dramatically in subsequent decades. Alberta's changing demographics will also be an

influential factor. Our aging population can be expected to contribute to an increasing number of persons with disabilities. This trend will also have significant economic and social implications.

We Stand on the Threshold of a New Era

While the 1990's are expected to bring new challenges, they also hold new promise. As is recognized in "Caring and Responsibility: A Statement of Social Policy for Alberta", social policy and economic policy can no longer be developed in isolation. It states:

> "The future economic growth of the Province depends on the development of capable and productive individuals. Indeed, social policy must lead if Albertans are to fulfill their expectations. . .it must form the supporting factor in the development of a strong economic environment."

Such a perspective is positive for all Albertans who have a disability. This philosophy provides a framework in which all individuals can exercise their right, responsibility, and capability to be financially contributing citizens. Such a framework also encourages the exploration of lifestyle and service delivery alternatives for persons with disabilities given the Alberta Government's commitment:

> "to foster individual self-reliance and provide positive opportunities for individuals to achieve their personal goals, to take responsibility for their actions, and to be contributing and caring members of Alberta society."

The challenge for future economic growth in Alberta also necessitates more effective integration of policy in the public and private sectors. For example, as traditional entry-level labour pools continue to decline in numbers, Alberta employers are becoming increasingly open to exploring under-utilized labour pools. Coordinated public and private policy could effectively assist persons with disabilities in acquiring appropriate training, transportation and access to employment as well as necessary technical aids, benefits, and family/ community support services.

Albertans with disabilities themselves continue to be effective public educators. Public attitudes are changing as Albertans increasingly gain opportunities for interaction with persons with disabilities. **As neighbours and co-workers come to know and work with individuals with disabilities, the focus of awareness will continue to shift to the person from the limitation, and to the ability from the disability.**

POLICY IN THE NEW ERA MUST BE INTEGRATED, ENABLING, AND PREVENTION FOCUSED

Public Policy towards Persons with Disabilities needs Transformation

Various policy fields such as Health, Social Services, Education, Employment, and Housing have historically been recognized as affecting persons with disabilities. However, limited coordination between these policy fields has contributed to today's collage of philosophy, policy and direction that has frustrated persons with disabilities.

A critical precursor to current and future public (government) policy revision is the definition of a policy field of disability. Such a policy field must be based on the premise that all policy with potential to affect persons with disabilities must contribute to and reinforce a consistent, comprehensive, and positive vision of persons with disabilities.

Policy affecting persons with disabilities must encompass three facets: social, economic and citizenship. Social policy requires commitment to a dignified and humane society ensuring quality of life for all Albertans. Within economic policy there needs to be recognition of the abilities and potential of disabled persons to make an economic contribution, and citizenship policy means making a commitment to full and equitable participation within the community life of the province.

Government and private sector policy must also be integrated if this positive vision for persons with disabilities is to be achieved. Recruitment practices, job design, and disability benefits, are only a few examples of private sector policy decisions which need to be compatible with public policy if persons with disabilities or employees who become disabled are to be enabled for employment.

A final component of the transformation of both public and private sector policy must be the replacement of the concept of cost with the concept of investment. Given our historical paternalistic assumptions, we have seen service delivery for persons with disabilities as necessitating ever-escalating financial expenditures. If policies and programs are designed to facilitate independence, refinement of ability, and self-reliance in individuals and families, then financial outlays can often be short-term in nature. And for those programs that are clearly long-term, expenditures can be minimized, becoming periodic in application as opposed to ongoing.

Public Values and Attitudes need Transformation

Transformation of public values and attitudes with regard to persons with disabilities is a mammoth and complex task. Yet it is only through the awareness and re-education of all Albertans regarding existing limiting assumptions, values and beliefs that Albertans with

disabilities can become full and equitable participants in Alberta society. Thus, there is a need for complementary initiatives by government, the private and not-for-profit sectors, communities, and individuals to mobilize attitudinal change.

Fundamental to such educational initiatives must be a focus on ability and potential. The outcome of our policy history has been the education of a generation of Albertans who perceive the "lack of ability" in persons with disabilities. We as Albertans must come to understand that persons with disabilities are not handicapped by their disability; rather, they are limited by inflexible social and physical environments which place the responsibility of adaptation on persons culturally defined as not "normal".

Many aspects of Alberta society are fundamentally shaped by government policy. As a result, it is critical that all government policy reflects positive, enabling values and attitudes towards persons with disabilities. There is need for a common set of policy principles to act as a foundation or framework for any public policy impacting Albertans with disabilities; compatibility with this framework would ensure the consistent promotion of positive values and attitudes.

Disability Policy must include a Focus on Prevention

In addition to defining a policy field of disability and the promotion of positive values and attitudes, public policy makers must recognize the interrelationship of lifestyle and the development of certain disabilities. This reality has been recognized in some cases; for example, education campaigns have been mounted to educate expectant mothers as to the detrimental affects of smoking and alcohol consumption on the development of the fetus. Much is left to be done, however. The occurrence of one of the most rapidly growing disabilities, i.e. brain injury, can be closely related to lifestyle choices of the high risk population of young adult males.

Thus, public policy must reflect an emphasis on the promotion of healthy individuals, healthy families, and healthy communities. The Premier's Commission on Future Health Care for Albertans has undertaken a commitment to develop policy that focuses on "innovation, promotion, and prevention". However, the responsibility for this promotion does not rest with public policy alone. The private sector, not-for-profit sector, communities, families, and individual Albertans all have critical roles to play if a shift from a "sickness" to a "wellness" perspective is to be achieved.

THE PREMIER'S COUNCIL FACES A CHALLENGE OF LEADERSHIP

The Premier's Council must Focus its Limited Resources

The nature of the challenge confronting the Premier's Council is immense and complex. Public expectations are high; consumers, advocacy groups, service agencies and government officials are looking to the Premier's Council to catalyze significant change. As a result, it is critical that the Premier's Council focus its resources on key priorities and produce visible results. To this end, the Premier's Council must produce specific short-term, medium-term, and long-term objectives to both sequence and focus its activities prior to the sunset period.

The Premier's Council also recognizes that it is only one of many players working to facilitate full and equal participation of Albertans with disabilities in Alberta society. In such an environment, cooperation and integration of initiatives serves to maximize the resources of all players, avoiding inefficiencies of duplication. Thus, **the Premier's Council does not see its role as one of competition with existing representational organizations nor does it see its role as a service provider.** Rather, the Premier's Council sees its role as that of a catalyst; Albertans with disabilities will be best served if the Premier's Council capitalizes on its unique position and comprehensive perspective. It must use this opportunity to facilitate integration, coalition, and collaboration between consumers, advocates, government departments, and private and not-for-profit sectors to mobilize change.

The Premier's Council must Lead in Policy Development

Given its cross-disability vantage point, the Premier's Council can play a critical role in identifying immediate and long-term priorities for policy review and development. These priorities include the following:

1) the need for the definition of a public policy field of disability to ensure a cross-disability perspective and consistency in all policy affecting Albertans with disabilities. Fundamental to such a policy field is the definition of policy principles which promote positive social roles for individuals with disabilities;

2) the need to ensure that existing and future public policy impacting persons with disabilities is developed in a comprehensive and integrated manner. Such an orientation would eliminate duplications in activities and increase efficiency; it would also rectify

oversights regarding the needs of certain persons or issues which fall between clear jurisdictional boundaries;

3) the need for long-term change agentry to ensure that public sector programs and services consistently mirror these policy principles;

4) the need for integration of public, private and not-for-profit policy to ensure consistent promotion of positive social roles for Albertans with disabilities.

The Premier's Council must Lead in Public Education

Public education continues to be a priority activity through which the most significant obstacles to Albertans with disabilities can be removed. In order to complement the initiatives undertaken by other organizations in this area, the Premier's Council's resources and energies are best channelled in the following areas:

1) the need to address a spectrum of deep-seated cultural beliefs which contribute to fear, limiting assumptions, and misunderstandings regarding individuals with disabilities. Initiatives would focus on the capability and potential of persons with disabilities to fulfill positive social roles;

2) the need to integrate public education with public policy so that the impetus for transformational change is accelerated.

The Premier's Council must Represent Its Constituents

The process that will be employed throughout the mandate of Council will place a heavy emphasis on consultation as a means of information gathering and validation.

Consumers and their families must be viewed as the primary "experts" in the direction that public education and policy development initiatives should take in elevating the status of disabled persons. As such, consultation with consumers will become an integral part of policy development and revision in this Province.

THE COUNCIL'S MISSION

The Council's draft Mission Statement is as follows:

"To enhance and promote the quality of life for all Albertans with disabilities."

This Mission Statement evolved directly from the Premier's Council Act which refers to "the opportunity for full and equal participation of persons with disabilities in the life of the Province".

THE COUNCIL'S PRINCIPLES

To focus pursuit of the mission, five principles have been proposed. These principles form the belief system that will guide Council's input into the two key areas of policy review and public education. These principles are interrelated and each must be viewed in the context of the others.

INDIVIDUAL RESPONSIBILITY AND PERSONAL CONTROL

- A system is needed that ensures individuals have the opportunity to make decisions and choices about issues affecting their lives.
- Mechanisms to support and assist individuals to make decisions must exist and should be provided in a way that will maximize freedom of individual choice, without denying the necessity to intervene where those decisions would clearly result in purposeful self-destruction or harm to others.
- Personal and financial supports must be in place for those who need them so that genuine options exist from which to choose.
- Freedom of choice must encompass the concept of "dignity of risk", meaning that people should also have the opportunity to risk making their own mistakes.

OPPORTUNITY FOR FULL PARTICIPATION IN COMMUNITY LIFE

- Individuals with disabilities must have a range of options for living and working in the community that provides opportunities to maximize participation in the life of the community of his or her choice.
- Support systems must be in place to facilitate and promote full participation in society.

PERSONAL CONTRIBUTION AND INHERENT WORTH

- Persons with disabilities must be recognized for their abilities and expenditure on training and support should be viewed as an investment in people.
- The concept of return on the investment must be expanded to include not only the economic contribution persons with disabilities will make in terms of taxes

and dollars reinvested in the community, but also contributions in the areas of community service and societal enrichment.

- Public education and policy must address the interrelationships of social, economic, and citizenship issues.

EQUITY OF OPPORTUNITY

- Barriers to participation in society that are purely a function of disability must be removed in order to create an "equal playing field". Among the barriers are lack of public awareness, lack of flexible and available support services, and financial costs directly related to a disability.
- The basic costs incurred directly as a result of a disability must be substantially reduced or eliminated on a universal basis, without the use of a means or asset test to determine eligibility.

CONSUMERS AS CONSULTANTS

- Consumers and their families must have input into policies that have potential to impact on the status of disabled persons.
- Consultation with consumers must occur as a matter of course whenever changes are being considered, thereby acknowledging the value of that input and the right of individuals to influence their government.

CONCLUSION

A unique opportunity exists in this Province to fundamentally change the lives of persons with disabilities. The Premier's Council can play an instrumental role in catalyzing that change. To be an effective agent of change, the Premier's Council must focus its limited resources on the most strategic targets. Those targets are primarily in the area of public policy and public education. Public policy can be amended and public values and attitudes can be adjusted. It is through pursuit of these changes that the Premier's Council on the Status of Persons with Disabilities will play its role in achieving a "Vision of Abilities in Alberta".